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No man's land: information needs and resources of men with metastatic castrate resistant prostate cancer

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Abstract

The majority of men treated for prostate cancer will eventually develop castrate resistant disease (CRPC) with metastases (mCRPC). There are several options for further treatment: chemotherapy, third-line hormone therapy, radium, immunotherapy and palliation. Current ASCO guidelines for survivors of prostate cancer recommend that an individual's information needs at all stages of disease are assessed, and that patients are provided with or referred to the appropriate sources for information and support. Earlier reviews have highlighted the dearth of such services and we wished to see if the situation had improved more recently. Unfortunately we conclude that there is still a lack of good quality congruent information easily accessible specifically for men with mCRPC and insufficient data regarding the risks, harms and benefits of different management plans. More research providing a clear evidence base about treatment consequences using patient reported outcome measures is required.

Introduction

Men with prostate cancer may face multiple treatment choices over the course of their illness, dependent on the stage of cancer at the time of diagnosis. Surgical and radiotherapy techniques have improved over the past decade and there are more drugs available offering prospects for an extended life of good quality. Unfortunately for the majority of men, progression to castrate resistant prostate cancer (CRPC) is universal [1] and treatments aimed at control of the cancer and amelioration of symptoms are required. The most common first line chemotherapy treatment for metastatic CRPC (mCRPC) is docetaxel plus prednisone, and more novel agents have expanded the treatment options, for example, Sipuleucel-T (an autologous cellular immunotherapy), cabazitaxel, enzalutamide and abiraterone [2-4]. All treatment choices involve highly complex decision-making processes for both the clinician and the patient, especially as discussions occur when the patient is understandably anxious, vulnerable and in need of reassurance.

The management of mCRPC involves a multidisciplinary team (MDT) approach, involving urologists, oncologists, palliative care and specialist nurses, so provision of accurate and consistent information is essential. When a team provide information to patients they need to be aware of the different informational roles played by their colleagues to ensure consistency [5]. Although health care professionals (HCPs) are the most frequently cited and trusted source of knowledge [6, 7], many patients seek additional information through support groups (either face-to-face or via the internet, chat rooms, blogs etc.), other web based information and phone-lines run by general cancer charities and specific prostate cancer charities [8]. In 2014, Macmillan had 4,334 requests for information related to prostate cancer, 2065 (31%) of which were to do with advanced disease, and fairly even split between patients and someone else such as a female family member, seeking that information [personal communication, 2015]. Similarly, Prostate Cancer UK had 9,923 contacts to their specialist nurses (April 2013-14); 48% of whom were diagnosed men who tended to ask about treatment options and side effects, whereas their partners called for

information about advanced disease and emotional support [personal communication, 2015].

Some Internet resources may contain dubious information about treatments or cures that are not applicable or unrealistic. HCPs treating men with mCRPC often supplement/complement their own information giving with that contained in National Cancer Charity pamphlets, or Prostate Cancer Charity leaflets that have links to their related websites. One interesting study developed a tool to evaluate how well the information on 9 breast and 7 prostate cancer charity websites [generated by www.google.uk.nhs] satisfied patient information needs [9]. The questions perceived as best answered were those concerned with genetic risk, different possible treatments and how they work, but overall there were 17 questions not answered thoroughly by any website, and areas least discussed were “when and how will I know if I have been cured?”, and “how do we know if the treatment is working?”. The quality of the information on websites varied also, with Charity based websites such as Macmillan rated as performing best for prostate cancer (74%) followed by the research sites Cancer Research UK (73%).

Existing appraisals of the information needs, expectations and experiences of treatment in men with prostate cancer have all commented on the lack of data for men and partners in the later stage of disease [10-11]. A series of studies with men with advanced prostate cancer, (the majority of whom were castrate resistant), their partners and health professionals identified three areas that needed attention [12-14]. These were a) treatments and associated side effects, b) progression of the disease (prospects for the future; end of life expectations), c) available supportive care services (including practical assistance). Many men reported not understanding the information given about treatments, how they worked and had difficulty getting answers to their questions. This was a fact acknowledged by the HCPs who were cognisant that men and their partners required more information about treatment and side effects, yet when attempting to address their concerns felt patients had difficulty understanding the information provided. Men reported difficulty getting clear details about their prognosis or what to expect in the future and thought facts were withheld and only provided if they asked. HCPs endorsed this and reported that men continually asked questions regarding disease progression, prognosis and their

anxieties about the end of life, including becoming a burden. Likewise, partners wanted the information but did not know what questions to ask. Discussions around these issues can be distressing for both patients and family members making some of them avoidant of the subject despite paradoxically needing information and support.

Men with mCRPC report significantly poorer quality of life (QoL) than other groups of men with prostate cancer with priority areas being fatigue, pain, and decreased physical activity [15], yet there are few patient reported quality of life data about the available treatments. Certain side effects may have far more relevance to the decision making process of men than is realised, for example what may be termed relatively minor symptoms by a clinician may in fact have a profound effect on certain individuals and strongly influence their treatment choices [16]. The American Society of Cancer Oncology (ASCO) and its European counterpart (ESMO) have published papers recently suggesting that new scales are needed to determine the magnitude of clinical benefit from a patient's perspective [17, 18].

The management options for men with mCRPC have changed with the advent of new therapies and the timing of treatments. Whilst this is all good news, there is still a lack of documented evidence on the effect disease and treatments have on patients' and families' overall quality of life and specific symptoms. More research is warranted in order to understand the impact of new treatments, physically and psychologically for this underserved population.

Conflict of Interest

Dr Jenkins & Professor Fallowfield's group received funding from Ph Associates & Sanofi UK to conduct a scoping exercise in the area of mCRPC. The funders had no role in the research, literature review or writing of this manuscript.

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